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Award Number: DAMD17-99-1-9310

TITLE: National Native American Breast Cancer Survivor's Network

PRINCIPAL INVESTIGATOR: Linda Burhansstipanov, Ph.D.

CONTRACTING ORGANIZATION: National Indian Health Board

Washington, DC 20001

REPORT DATE: September 2003

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PREPARED FOR: U.S. Army Medical Research and Materiel Command

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Final (1 Sep 1999 - 31 Aug 2003)

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6. AUTHOR(S)

Linda Burhansstipanov, Ph.D.

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)

National Indian Health Board Washington, DC 20001

8. PERFORMING ORGANIZATION REPORT NUMBER

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9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)

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12b. DISTRIBUTION CODE

13. ABSTRACT (Maximum 200 Words)

The Native American Breast Cancer Survivors' Support Network (DAMD17-99-1-9310) is a three year-project supported by the Department of Defense. This project is being conducted by Native American Cancer Research in collaboration and partnership with the National Indian Health Board. The purpose of this project is to improve the survival from breast cancer and quality of life after being diagnosed with breast cancer for both the patient and loved ones of the cancer patient. The study objectives follow: (a) using key and well organized Native American cancer leaders form geographically diverse regions of the country, identify, and recruit Native American breast cancer patients into the survivor's network and database; and (b) refine, and evaluate the survivor's database to determine patterns of disease and patterns of care experienced by Native American breast cancer survivors. The intended population is Native American breast cancer patients, both genders, ages 20 and older, living anywhere on the North American continent. Preliminary findings include documentation that Native breast cancer survivors are not receiving quality care, less than one-third have access to insurance (and thus access to improved quality of care) and standard protocols used with other survivors are ineffective with Native cancer survivors.

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4. Introduction

The Native American Breast Cancer Survivors' Support Network (DAMD17-99-1-9310) was a three year-project supported by the Department of Defense from March 2000 through February 28, 2003 (grant period approved by DoD April 10, 2001). This project was being conducted by Native American Cancer Research in collaboration and partnership with the National Indian Health Board, Mayo Clinic's, "The American Indian / Alaska Native Initiative on Cancer" ("Spirit of E.A.G.L.E.S.") [U01 CA86098]. The project addresses various support issues for those dealing with breast cancer and to learn more about how cancer is affecting Native communities. The purpose of this project is to improve the survival from breast cancer and quality of life after being diagnosed with breast cancer for both the patient and loved ones of the cancer patient. The study objectives follow: (a) Using key and well recognized Native American cancer leaders from geographically diverse regions of the country, identify and recruit Native American breast cancer patients into the survivors' network and database; and (b) Refine, and evaluate the survivor's database to determine patterns of disease and patterns of care experienced by Native American breast cancer survivors. The intended population is Native American breast cancer patients, both genders, ages 20 and older, living anywhere on the North American continent.

5. Body

As has been reported previously, the medical record component of the protocol was eliminated in 2002. According to the previous project director, there are 360 women enrolled in the Network. However, that program director destroyed the database and NACR staff has been recollecting all data during the last nine months.

Task 1: Refine the plan for active recruitment into the survivors' database for all participants of

the Social Network

The task has been accomplished. We have continued to refine the recruitment plan and now encourage volunteer referrals from community members. This is proving to be a better source of recruitment than were key leaders and Native organizations or Cancer Centers.

TASK 2. Collection of survivors' intake data

| Table 1: Survivors' Database Status | |
|---|-----|
| Survivors eligible for DoD survey | 118 |
| Service users who are now eligible for DoD survey | 10 |
| Survivors' for whom we have no information (i.e., former director's possession) | 95 |
| partial survey information | 28 |
| unable to contact | 19 |
| Loved Ones of cancer patients | 60 |
| deceased | 15 |
| Total | 345 |

Task 3. Collection of medical records and verification of self-reported data

As per previous annual reports, this function was eliminated from the project due to the elevated number of errors found on medical records. In addition, with HIPAA, collection of

medical records was cumbersome and of limited use. NACR removed the section from the informed consent process requesting copies of cancer-related medical records. Of the medical records collected by NACR Headquarters, almost none included information to validate staging (i.e., metastases, histologic grade, lymph node involvement).

Of the records collected, most, but not all had treatment specified, but no staging information was included.

Task 4: Refine database

The database has been revised. Dr. Dignan currently loads the data into ACCESS, then converts to SAS and/or SPSS.

Cross tabulation are in process of being conducted with those surveys for which we have complete data.

Task 5: Evaluation of the Database

Since NACR staff and contractors are in the process of re-collecting and re-loading all data collected since March 2002, we are only now beginning to do any additional data runs.

6: Key Research / Preliminary Findings

- Approximately one-fourth of the Native breast cancer survivors have diabetes in addition to their breast cancer. Their oncologist and diabetes physicians almost never have any interaction and the subsequent treatments for both diseases frequently interact adversely with one another (e.g., kidney and circulation problems associated with concurrent glucose controlling medication and chemotherapy).
- Less than one-third of the Native survivors have health insurance -- regardless of whether they live in the urban or rural community.
- We initially thought we would see differences between urban and reservation communities. In actuality, the pattern seems to be (a) those who are dependent on Indian Health Service (IHS) Contracted Health Services (CHS) as compared to those who have private insurance. Those with private insurance are able to access quality cancer services, regardless of whether they live in the urban or reservation area. Those reliant on IHS care have less access to quality, standard cancer care and greater delays in accessing care. For example, the interval from biopsy to initiation of cancer care is more than six months in selected tribal communities. This varies greatly from location to location, and is in part dependent upon (a) IHS/Tribal clinic; (b) calendar month of the year (i.e., CHS monies frequently are depleted by June for most clinics); (c) tribal priority ranking of cancer for CHS monies (i.e., if prioritized lower than 8, the patient may not be referred at all); (d) daily living issues unrelated to availability of CHS monies (e.g., single mother responsible for small children who may be gone for 3-6 months to complete the treatment cycle needs to find someone to care for the children during her absence).
- The norm for IHS CHS referred patients is no access to a second opinion for their diagnosis.
- To date, almost half of all of the breast cancer patients have been identified with cancer prior to age 50, which may indicate a different pattern of cancer in comparison to white women.

7. Reportable Outcomes

A. In submission

 Restivo TS, Weiner D, Burhansstipanov L, Krebs LU. From survivorship to thrivership: Native peoples weaving a healthy life with cancer. Resubmitted January 2004 to *Journal of Cancer Education*.

B. Peer Reviewed Publications

- Burhansstipanov L, Krebs LU, Bradley A, Gamito E, Osborn K, Dignan MB, Kaur JS. Lessons Learned while Developing "Clinical Trials Education for Native Americans" Curriculum. Cancer Control Supplement: Cancer, Culture and Literacy: September/October 2003: 10: 5: 29-36
- 2. Burhansstipanov L, Gilbert A, LaMarca K, and Krebs LU. An Innovative Path to Improving Cancer Care in Indian Country. *Public Health Reports*: 2002: 116: 5: 424-433.
- 3. Burhansstipanov L and Hollow W. Native American Cultural Aspects of Nursing Oncology Care. Seminars in Oncology Nursing: 2001: 17: 3: 206-219.
- 4. Burhansstipanov L. Chapter 10: Cancer: A Growing Problem. eds. Mim Dixon and Yvette Roubideaux. *Promises to Keep.* Washington, D.C., American Public Health Association, 2001.

Patents and informatics are not appropriate to this study.

8. Conclusions

Although the process for this Network is quite unique from support programs implemented within other cultures, this project has continue to expand. Based upon the preliminary information, we have received funding from the National Susan G. Komen Breast Cancer Foundation to begin the development of tailored, interactive education modules to improve quality of life. NACR has also received a high score from the NCI to develop approximately seven more such modules.

9. References

10. Appendices

Burhansstipanov L, Krebs LU, Bradley A, Gamito E, Osborn K, Dignan MB, Kaur JS. Lessons Learned while Developing "Clinical Trials Education for Native Americans" Curriculum. *Cancer Control Supplement: Cancer, Culture and Literacy*: September/October 2003: 10: 5: 29-36 (the other articles referred to were included with previous annual reports to the DoD)

11. Binding. As per instructions, this report is stapled in upper left hand corner and is camera-ready.

12. Final Reports

a. Meeting Abstracts The Native American Breast Cancer Survivors' Support Network has been presented at the following meetings:

- Presented, "Native American Breast Cancer Support -- Training Outreach Workers". Rincon Rancheria, Pauma, CA. January 5-6, 1999.
- Presented, "Native American Breast Cancer Survivors' Support Network.' National Susan G.
 Komen Breast Cancer Foundation Affiliate Meeting, Dallas, TX. February 5, 1999.
- Presented a poster on, "Native American Breast Cancer Survivors' Support Network.' for the National Cancer Institute Office of Cancer Survivorship Annual Conference. Washington, DC. March 8-9, 1999.
- Presented, "National Native American Breast Cancer Survivors Support Network" to the Network for Cancer Control Research among American Indian and Alaska Native Populations, supported by the NCI. Washington, DC. April 9-10, 1999.
- Presented, Native American cancer survivor: how the community can help. Rincon Reservation, CA May 19, 1999.
- Presented, "National Native American Cancer Survivors Support Network" to the Northwest Portland Area Indian Health Board. Reno, Nevada. July 15, 1999.
- Presented, "National Native American Cancer Survivors' Support Network" CDC Challenges of Comprehensive Cancer Control. Atlanta, GA. September 9, 1999.
- Presented, "National Native American Cancer Survivors' Support Network" to the National Susan G. Komen Breast Cancer Foundation Grantee's Conference. Dallas, TX. October 4, 1999.
- Presented, "National Native American Cancer Survivors' Support Network" American Public Health Association. Chicago, IL. November 8, 1999.

- Presented, "Cancer," to the Native Elder's Research Center (NERC), Resource Center for Minority Aging Research (RCMAR), University of Colorado Health Sciences Center, Denver, CO. January 9, 2000.
- Co-Presented with Terrie Restivo, "National Native American Cancer Survivors' Support Network" to the 7th Biennial Symposium on Minorities and Medically Underserved Populations and Cancer. Washington, D.C., February 12, 2000.
- Co-Presented with Alisa Gilbert, "National Native American Cancer Survivors' Support Network" to the University of Oklahoma's Wellness and Women Conference. San Diego, CA. March 22, 2000.
- Presented, "Native American Culturally Competent and Community Driven Research" to the OHSU Native American Cancer Researchers' Training Program. March 23, 2000.
- Presented, "Native American Health Issues, Lessons Learned from Community-based Interventions, and Overview of Native Cancer Projects" to the University of North Carolina Summer Public Health Research Videoconference on Minority Health, NC. June 12, 2000.
- Presented, "Native American Cancer Research and Community-Driven Interventions" to the National Cancer Institute Research Fellows, Rockville, M.D.. August 1, 2000.
- Presented, "National Native American Cancer Survivors' Support Network: what works and what does not." National Susan G. Komen Breast Cancer Foundation Grantee meeting. Washington, D.C., September 17-18, 2000.

- Presented on panel for town hall meeting, "Issues Facing the Underserved in Breast Cancer: Native Americans." National Susan G. Komen Breast Cancer Foundation Grantee meeting. Washington, D.C., September 19, 2000.
- Presented, "Native American Cancer Issues". CH 509 Graduate Seminar in Health Behavior, University of Northern Colorado, Greeley, CO, November 7, 2000.
- Presented, "National Native American Cancer Survivors' Support Network: Preliminary Data"
 American Public Health Association, Boston, MA, November 13, 2000.

- Presented, Training #1 for "Native American Breast Cancer Support in Southern California Indian Communities." Rincon Reservation, CA, January 8-9, 2001
- Presented, "National Native American Cancer Survivors' Support Network" Intercultural Cancer Council National Network, Washington, DC. February 6, 2001
- Presented, "National Native American Cancer Survivors' Support Network: Preliminary Findings." University of Oklahoma's Wellness and Women Meeting, San Diego, CA March 5, 2001
- Presented, Training #2 for "Native American Breast Cancer Support in Southern California Indian Communities." Barona Reservation, CA, March 8, 2001
- Facilitated and presented multiple sessions during 3 day, "CDC Tribal Outreach Training," (which included preliminary data about Native American breast cancer survivors), Denver, CO, May 2-4, 2001
- Presented, "Native American Cultural Issues affecting Cancer Pain Relief." (which included preliminary data from the Native American breast cancer survivors), American Alliance of Cancer Pain Initiatives, Madison, WI, June 14, 2001.
- Presented, "Native American Cancer Research Cultural Issues." National Cancer Institute Research Fellows Training. Bethesda, MD. July 31, 2001
- Presented poster, "National Native American Cancer Survivors' Support Network". Association of American Indian Physicians, Albuquerque, NM. August 11, 2001.
- Presented poster, "National Native American Cancer Survivors' Support Network". Centers for Disease Control and Prevention 2001 Cancer Conference. Atlanta, GA. September 5-7, 2001.
- Presented, "Preliminary Data from the 'National Native American Cancer Survivors' Support Network'" American Public Health Association, Atlanta, GA, October 22, 2001.
- Presented, "Clinical Trials Education for Native Americans'" American Public Health Association, Atlanta, GA, October 23, 2001.
- Co-Presented, "Preliminary Data from the 'National Native American Cancer Survivors' Support Network'" Native American Cancer Survivors' / Thrivers' Conference. Scottsdale, AZ, November 9, 2001.
- Presented, "Clinical Trials Education for Native Americans: Native cancer patients have a right to choose." Native American Cancer Survivors' / Thrivers' Conference. Scottsdale, AZ, November 9, 2001.
- Co-Presented with Judith Kaur, "Clinical Trials Education for Native Americans." 5th National
 Native American Cancer Conference: Changing Patterns" Scottsdale, AZ, November 12, 2001.

- Presented, "Preliminary Data from the 'National Native American Cancer Survivors' Support Network'" 5th National Native American Cancer Conference: Changing Patterns" Scottsdale, AZ, November 12, 2001.
- Co-Presented with Mark McClees and Rick Strickland (substituted for Mark Dignan who was ill),
 "The Native IRB Process". 5th National Native American Cancer Conference: Changing Patterns" Scottsdale, AZ, November 13, 2001.

- Presented, "Community-driven interventions", Cancer Cultural and Literacy Institute Training (included preliminary findings from the "National Native American Cancer Survivors' Support Network"), Clearwater, FL, January 8, 2002
- Presented, "Cancer among Native Americans: Emerging Patterns of Disease and Disparities in Accessing Care," (included preliminary findings from the "National Native American Cancer Survivors' Support Network") for the Carnival Cruise Fund-raising event for American Cancer Society and Native American Cancer Research. California and Mexico. February 1, 2002.
- Presented "Clinical Trials Education for Native Americans: Lessons Learned" (included preliminary findings from the "National Native American Cancer Survivors' Support Network").
 8th Biennial Symposium on Minorities, the Medically Underserved and Cancer. Washington, D.C. February 7, 2002.
- Presented poster for the "National Native American Cancer Survivors' Support Network" 8th Biennial Symposium on Minorities, the Medically Underserved and Cancer. Washington, D.C. February 9, 2002.
- Presented, "Clinical Trials Education for Native Americans" at the Native Wellness and Healing Institutes "All my Relations" conference, Reno, NV, February 25, 2002.
- Assisted / mentored Ms. Terrie Restivo in her presentation, "Native American Cancer Survivor Support Circles" (included preliminary findings from the "National Native American Cancer Survivors' Support Network") for the Native Wellness and Healing Institutes "All my Relations" conference, Reno, NV February 27, 2002.
- Taped presentation for Dr. Lori Jervis' Life Planning Teleconference class, "Cancer and Native Americans," (included preliminary findings from the "National Native American Cancer Survivors' Support Network") Denver, CO March 20, 2002.
- Judy Hariton, Network Coordinator, presented poster session for American Association for Cancer Research's Survivor Program. March 20, 2002.
- Presented keynote, "Diversity and Women's Health Issues" University of Nebraska's Women's Health Conference (included preliminary findings from the "National Native American Cancer Survivors' Support Network"). April 5, 2002.
- Presented general session, "Community-based Health Interventions" (included preliminary findings from the "National Native American Cancer Survivors' Support Network") University of Nebraska's Women's Health Conference. April 5, 2002.
- Presented 2-day training for southern California, "Helping Path" tribal programs on cancer clusters, leukemia, new treatments, non-profit processes and preliminary findings from the "National Native American Cancer Survivors' Support Network". Rincon Tribal Center, CA. May 20-21, 2002.
- Alisa Gilbert presented poster session, NIH "Cancer Survivorship: Resilience Across the Lifespan", Hilton Washington & Towers Hotel, Washington, D.C., June 2-4, 2002.

- Presented 2 ½ day training to help the states improve their working relationships with tribal Nations and programs (included preliminary findings from the "National Native American Cancer Survivors' Support Network"). Albuquerque, NM. June 11-13, 2002.
- Presented via teleconference, "Community-based Interventions: Making the Messages Work" (included preliminary findings from the "National Native American Cancer Survivors' Support Network") to the Oregon Health Sciences University, "Native Cancer Researchers Training Program". Portland, OR. June 20, 2002.
- Presented, "Cancer among Native Americans" for the NCI's fellows course, "The Principles and Practice of Cancer Prevention and Control." (included preliminary findings from the "National Native American Cancer Survivors' Support Network") Rockville, MD. July 29, 2002.
- Presented, "American Indian Alaska Native Cancer Update" for the CDC Tribal Program Directors, Anchorage, AK, July 30, 2002
- Co-presented with Alisa Gilbert, "Cancer Education Resources," (included preliminary findings from the "National Native American Cancer Survivors' Support Network") for the Alaska Cancer Conference, Anchorage, AK July 31, 2002.
- Presented, "Clinical Trials Education for Native Americans" for the Association for American Indian Physicians, Anchorage, AK August 2, 2002.
- Presented, "Disparities and cancer care among Native Americans" (included preliminary findings from the "National Native American Cancer Survivors' Support Network") to the Annual Colorado Cancer Conference, Colorado Springs, CO August 22, 2002.
- Facilitated and key trainer for the National Indian Women's Health Resource Center's CDC Tribal Outreach Training, (included preliminary findings from the "National Native American Cancer Survivors' Support Network") Portland, OR August 27-29, 2002.
- Judy Hariton presented both orally and a poster session to Era of Hope Department of Defense Breast Cancer Research Program Meeting, Tampa, FL, September 29, 2002.
- Presented keynote, Understanding Cancer (which included preliminary findings from the "National Native American Cancer Survivors' Support Network", Shakopee Mdewakanton Sioux Community Cancer Conference, Prior Lake, MN, October 7, 2002.
- Presented, "Clinical Trials Education for Native Americans: Lessons Learned" at the American Public Health Association Annual Conference, Philadelphia, PA, November 11, 2002.

- Presented with Nina Wampler, "National Native American Cancer Survivors' Support Network" to the Native Men and Women's Wellness Conference, Mesa, AZ, February 12, 2003.
- NACR Staff displayed exhibit highlighting the "National Native American Cancer Survivors' Support Network" throughout the Native Men and Women's Wellness Conference, Mesa, AZ, February 12, 2003.
- NACR Staff displayed exhibit highlighting the "National Native American Cancer Survivors' Support Network" throughout the Native Men and Women's Wellness Conference, Mesa, AZ, February 12, 2003.
- Presented keynote, "Diversity and Cancer Care Issues", Wyoming Minority Health Conference, Cheyenne, WY, April 30, 2003.
- Presented "Breakout Session A: It's Evident, It's Relevant, It's Cultural", Wyoming Minority Health Conference, Cheyenne, WY, April 30, 2003.

- Presented, "Outreach Strategies", to the Montana American Indian Women's Health Consortium, Missoula, MT, May 5, 2003.
- Presented keynote, "Lessons Learned to improving partnerships between Tribal Nations and State Programs", Spring Montana Public Health Meeting, Missoula, MT, May 6, 2003.
- Presented, "Lessons Learned from the Genetic Education for Native Americans Study", Indian Health Service Research Conference, Scottsdale, AZ, May 14, 2003.
- Presented, "Lessons Learned from the Clinical Trials Education for Native Americans Study,"
 Indian Health Service Research Conference, Scottsdale, AZ, May 14, 2003.
- Presented inservice training, "Improving Communication / Presentation Skills". Pine, CO June 2, 2003
- Presented inservice training, "Preparing to do Workshops". Pine, CO
 June 2, 2003
- Presented keynote, "To boldly go where no woman has gone before". 6th Annual Susan G.
 Komen Mission Conference, Delivering the Promise Washington, DC June 9, 2003
- Presented, "Cultural Consideration in Community-based Cancer/Health Interventions" Native Researchers Cancer Control Training Program, OHSU Portland, OR June 19, 2003
- Presented, "Cancer Control Study Designs", Native Researchers Cancer Control Training
 Program, OHSU
 Portland, OR June 19, 2003
- Presented, "Outreach Strategies Successful in Indian Country". Native Researchers Cancer Control Training Program, OHSU Portland, OR June 19, 2003
- Judy Hariton, presented poster for the scientist-survivors' program of the American Association of Cancer Research, Washington, D.C. July 2003.
- Co-presented with Dr. Judith Kaur and Ms. Alice Bradley, "Clinical Trials Education for Native Americans" to the Association for American Indian Physicians (AAIP). Albuquerque, NM August 1. 2003
- Co-presented with Dr. Linda U. Krebs, Ms. Alice Bradley, and Mr. Eduard Gamito, "Clinical Trials Education for Native Americans" 2 days training, Denver, CO; August 6-7, 2003.
- Co-presented with Dr. Linda U. Krebs, Mr. Eduard Gamito, "Clinical Trials Education for Colorado Providers" to the Colorado Cancer Coalition Conference Denver, CO, August 11, 2003.
- Co-presented, "Strategies to Address Disparities in Accessing Quality Cancer Care" to the Colorado Cancer Coalition Conference Denver, CO, August 11, 2003.
- Presented, "Learning to Communicate for Cancer Control: Respecting Custom and Culture" at the annual Centers for Disease Control and Prevention Cancer Conference, Atlanta, GA; September 17, 2003.
- Presented, "Cancer Disparities in Indian Country" at the annual Centers for Disease Control and Prevention Cancer Conference. Atlanta, GA; September 15, 2003.
- Presented, "National Native American Cancer Survivors' Support Network" at the annual Centers for Disease Control and Prevention Cancer Conference. Atlanta, GA; September 16, 2003.
- Co-presented, "Clinical Trials Education for Native Americans" at the National Indian Health Board consumer's conference, Minneapolis, MN; September 30, 2003.
- Co-presented keynote with Dr. Judith S. Kaur, "Cancer overview: Where are we one year later?" Shakopee, Northern Plains Regional American Indian Cancer Conference Prior Lake, MN; October 6, 2003.

Presented, "Native American Cancer Issues" for Dr. Kathy Zavela's graduate course, Greeley,
 CO; October 13, 2003.

b. Articles in Peer Reviewed Journals

- 1) Burhansstipanov L, Krebs LU, Bradley A, Gamito E, Osborn K, Dignan MB, Kaur JS. Lessons Learned while Developing "Clinical Trials Education for Native Americans" Curriculum. *Cancer Control Supplement: Cancer, Culture and Literacy*: September/October 2003: 10: 5: 29-36
- 2) Burhansstipanov L, Gilbert A, LaMarca K, Krebs LU. An innovative path to improving cancer care in Indian Country. *Public Health Reports*. 2002: 116: 5: 424-433.
- 3) Burhansstipanov L and Hollow W. Native American Cultural Aspects of Nursing Oncology Care. Seminars in Oncology Nursing: 2001: 17: 3: 206-219.
- 4) Burhansstipanov L. Chapter 10: Cancer: A Growing Problem. eds. Mim Dixon and Yvette Roubideaux. *Promises to Keep.* Washington, D.C., American Public Health Association, 2001.

c. Personnel Receiving Partial Pay for the Research Effort

| Name | Role on Project | Native American |
|--|---|-----------------|
| Linda Burhansstipanov, M.S.P.H., Dr.P.H. | P.I. | yes |
| Lisa Castro | Grants Manager | |
| Richard E. Clark | Data / Computer Programming; no longer in this role | |
| Mark Dignan, Ph.D. | Co-Investigator / Data Manager | |
| Alisa Gilbert | Director: no longer in this role | yes |
| Judy Hariton | Coordinator | |
| Lisa Harjo | Patient Advocate | yes |
| Tvhokne Harjo | Data coding and loading; <i>no</i> longer in this role | yes |
| Khari LaMarca, M.P.H. | Survivor Advocate; <i>no longer in this role</i> | yes |
| Rose Lee | Patient Advocate | yes |
| Terri Lynne Rattler | Patient Advocate | yes |
| Kathy Valencia | Patient Advocate | yes |

Advisory Board members and Survivor Advocates who receive partial compensation for work performed for the Network

| Name | Role on Project | Native American | |
|----------------------------------|---------------------------------------|-----------------|--|
| Alice Bradley, MA | Advisory Board - in kind contribution | | |
| Jennie Joe, PhD | Advisory Board / Survivor | Yes | |
| Judith S. Kaur, M.D. oncologists | Advisory Board | Yes | |
| Linda Krebs, RN, AOCN, Ph.D. | Advisory Board | | |
| Jody Pelusi, RN AOCN, PhD | Survivor Advocate | | |
| Terri Restivo | Survivor Advocate / Survivor | Yes | |
| Jo Stand | Survivor Advocate/ Survivor | Yes | |
| Caren Trujillo | Survivor Advocate / FDR | Yes | |
| Nina Wampler | Survivor Advocate / FDR | Yes | |
| Diane Weiner | Survivor Advocate / Faculty | | |